

Patient Story – Chris Harmer

As a child, you assume that most things are normal. When I was frightened at night, I could sometimes hear my heart beating fast. Then it would pause, big thump, and beat normally. But I thought that was normal. In my forties, I started to have occasional near-faints, usually at work, sometimes with loss of vision. I was afraid it was petit mal, and told no-one, not even my wife.

Holidaying in Scotland, my wife and I climbed Ben Nevis: a challenge, but at that time we were well used to mountain walking. Returning to our car, I sat down and had an awful drifting away sensation accompanied by feelings of dread, fear and panic. It lasted perhaps 20 or 30 seconds, but then kept recurring every few minutes. It subsided after a trip to the Angus Steak House!

The problem then began to recur with long walks and work stress, and I realised it was a heart rhythm problem when I also started to get attacks of a banging, highly irregular heart rhythm that could last for hours.

I saw my GP, who referred me to the cardiology clinic at the local general hospital. After the usual echocardiogram, holter monitor, ABPM, exercise test, etc, nothing was found and I was pronounced fit and well by the cardiology consultant, but perhaps suffering from stress.

The problems recurred. As an electronics engineer by profession, I decided that I had to devise a means of diagnosis myself. I had an athletic heart rate monitor which transmitted cordlessly from its chest electrodes to a monitor on the wrist. Referring to the device's patent I discovered that the heart rate information was being transmitted by magnetic pulses. I soon realised that I could pick up these pulses using a magnetic coil sensor intended for telephone monitoring which could then be fed to a pocket dictaphone. Armed with tape recordings of tachycardia and a-fib, I visited my GP who was amazed that I had diagnosed myself with fifty pounds worth of off-the-shelf electronics. I was re-referred.

The day before my cardiology appointment I was having a particularly stressful day at work, and started my worst ever string of repeating tachycardia events. I struggled home by bus, and went to bed hoping that the problem would ease with relaxation and sleep. At 4am I woke in panic feeling dreadful, and after an ECG in casualty I was whisked to the cardiac ward on oxygen with a defib pack on the trolley "just in case". The following day, during ward rounds, I apologised to the consultant that I would not be attending his outpatient clinic that day! I went on amiodarone, which was at once effective and awful, and put on the waiting list for the then-new EP clinic at the BRI, Bristol.

I did not get on with amiodarone. Weight gain, visual and skin problems, and finally, when it was starting to "do in" my thyroid, my BRI appointment came through. Jon Pitts-Crick took me off amiodarone immediately, and I was offered a treatment called "electrophysiological studies". A few months later, the EP studies resulted in a diagnosis of atypical fast-slow AV node re-entry tachycardia. At that time, it was deemed unsafe to try to ablate a problem within the AV node, but intravenous adenosine would terminate an episode of rapidly re-occurring tachycardia events. So I was sent away with sotalol to help keep me in sinus. I researched my condition, and became fed up with my six-monthly cardiology clinic appointments where I would be faced with a junior doctor who seemed to know less about my condition than I did. After a shouted "have you been getting any palpitations, Mr Harmer?" I rather despairingly lost patience and discharged myself from the clinic as I felt continuing appointments were a waste of their time and mine.

For 12 years I was under purely GP control, with varying single tachycardia events and bouts of a-fib. I can often stop the a-fib in its tracks by a prompt valsalva manoeuvre, which I was taught by my GP. Work pressure and stress worsened, I was having more time off with a-fib attacks, and my then manager thought I was "swinging the lead". "What's wrong with you, Chris? I can't see anything wrong with you". A new, younger manager became a lot more sympathetic when he ended up in cardiology with a persistent arrhythmia which had to be

terminated by cardioversion. But the work stress continued, and I was repeatedly turned down for voluntary redundancy as I was “much too valuable a member of the team”. Finally, in 2001 and aged 55, I took early retirement to escape the stress.

I regret retiring now as we are increasingly financially challenged, but at the time it seemed the only way out. And for a time my arrhythmias were, indeed, better. In 2004 I became involved in local politics, and last year I stood as a district councillor in two elections. The day before polling day, I came in for lunch after a hard morning’s canvassing, sat in an armchair, felt a tachycardia coming on, shouted for my wife, and passed out. When I came round, I was in a bad a-fib which lasted for 24 hours. I gave up politics! I also did more research on my arrhythmias, and came across the Arrhythmia Alliance on the web.

I attended the Europe-AF conference in London on 15th June this year, and heard a talk by Tara Meredith, an arrhythmia nurse specialist, on the rapid access clinic at the John Radcliffe, Oxford. During tea, Tara confirmed that the JR took patients from my area, and advised that my GP could refer me via the new choose-and-book system.

My GP said no, no, I would have to be referred to the JR from the consultant at the local general hospital, and that referral to the JR was really only for exceptional cases. I suggested he try choose-and-book. He hadn’t used it before, but was happy to “give it a go” online. “Here we are – John Radcliffe – electrophysiology – you’re right, I can refer you direct, but I expect it’s a long wait – let’s see – yes, you see, 28 **DAYS**??? Gosh, I didn’t expect it to be that quick”.

I attended the JR clinic on 28th August, and saw Tara for a very thorough history-taking session which took around an hour. She then held a quick case conference while I waited, and returned with Dr Tomlinson, an EP, who offered several options for treatment. He was also interested in my novel method of self-diagnosis, particularly its low cost! I am currently being assessed for “pill-in-the-pocket” flecainide for terminating a-fib, and I am pondering whether or not to take the offer of an ablation for my tachycardia: I am worried by the remote possibility of ending up with a pacemaker. As an electronics engineer I have no trust in electronic devices! But I sense that I will have the ablation in the end.

Chris H 29th October 2008.

Post Script

In October 2009 I had a cardiac ablation procedure at the John Radcliffe, Oxford. What they found was not quite what they had assumed, and the procedure took nearer four hours than the two hours that I had been given to expect. They had difficulty keeping the tachycardia going for long enough to trace the exact source, but they ablated a likely area. One possible re-entrant was too close to my AV node to be able to ablate safely, so I went away unsure as to what the improvement might be. Nearly five months later I am almost free of symptoms (touch wood!) although I am still affected by some foods causing mainly short bouts of ectopics. I still take a daily low dose of Bisoprolol and Flecainide, and although the John Radcliffe says I can try stopping all medication, so far I haven’t had the courage to try going completely without. If I really watch what I eat then I have been up to over two weeks without a missed beat. Wow, I have my life back! It’s taking some getting used to.

Chris H 3rd March 2010.